There is much to be learned from the experiences of direct support workers. For agencies supporting people with developmental disabilities; for elected officials deciding how public money is spent; for people with disabilities and their families. If you are reading this, you are likely aware that support workers generally have low pay, low benefits, and low status. Yet they do very important work.

As more citizens previously separated from the community begin to have meaningful lives, and as options increase for individuals to move out from their family’s home, we see a greater need for direct support workers. It is a happy fact that as more people with disabilities gain opportunities for individualized support to live and work in the community, more personal assistants are needed.

As agencies employing direct care staff learn to listen more closely to them, there is more reason to be hopeful about the future of community life for people with disabilities. Hearing what staff on the frontlines have to say can and should lead to better support of staff and people with disabilities.

Despite the great diversity among direct support staff, certain messages continue to rise to the surface. These recurring themes, if heard and acted upon, can result in better support to staff, a reduction in turnover, and improved quality of life for people being served. This “Top Ten” list reflects many of these themes, as heard over time from support workers in Wisconsin and elsewhere. It is not an exhaustive list, nor are the points in a particular order. (Please note: “Take this job and shove it” didn’t make the top 10.)

Let’s look at the list from the point of view of “Barb”, a direct support worker who assists “Theresa”, and what she would say to the agency she works for. They have worked together for two years, since Theresa moved out of a large facility into her own home.

1. Help me get off to a good start.
Here are some thoughts as I reflect on when I began working with Theresa, and knowing what I know now. There’s a lot to absorb at the start of a new job. I need to learn about the agency, and mostly I need to learn about Theresa. And she needs to learn about me. Remember when you started – that feeling of being new? I am excited, and I am happy to have been offered this job, and I’m a bit scared. Everything is new, I have a lot of responsibility, and I want to do a good job.

I would like you to tell me all about Theresa, and give Theresa plenty of room to tell me all about herself, in whatever ways she can. I mean the things I need to know to do my job, and the things Theresa wants me to know. I don’t expect Theresa’s life to be an open book for me to read – after all, we’re just meeting each other. But there are things I need to
know, most of which are things Theresa wants me to know. What’s important to her? What are the musts and the must-nots? Help me learn how these influence my required job duties, and be specific about what those duties are.

2. Be aware of my isolation.
This is a one-to-one job. I like it that way. Being able to spend time assisting Theresa and having the kind of relationship we do works for me. Most of the time, it is a satisfying way to spend my work time. But sometimes I feel pretty alone. I don’t have co-workers around much. I don’t often experience working with a team, even though there are others who support Theresa.

It would be nice to occasionally have get-togethers with other people who do this kind of work, to find out what it’s like for them, or why they got involved doing this. Or to talk about what a great day Theresa and I just had – or what a difficult day we just had. A lot of people meet friends through work, and with direct support that can be difficult.

3. Ask for my input on issues related to my job.
As Theresa and I get to know each other better over time, I will gain some valuable insights about her. My knowledge and understanding could be useful in the support we’re all providing for her. See my role over time with Theresa evolve from “Tell me what I need to know and do” in the beginning to “Let me tell you what I’m learning that we all need to know” as time goes on. I become a valuable resource for determining with you and Theresa what the agency’s support should look like. Also, I begin to seek ways that I can stretch in my job – to try new things, to learn more, and to grow.

4. Communication and supervision are important to me.
There are several people directly involved with Theresa’s support. We need to get together on a regular basis, both for sharing important information and for supporting each other.

As my supervisor, talk with me about supervision. It may mean something different to me than it does to you. Getting to know each other is important. Having regular contact is important. Checking in with me (rather than checking up on me) is important. Letting me know when you think things are going well, and not just when something is wrong, is important. Being available when I need to talk to you, or making sure someone else is, and getting back to me in a timely fashion when I try to reach you – these are all important.

When we do talk, I need you to hear what I’m saying. I know you’re busy, and time is tight. But please listen to me. Find out what’s on my mind. If you tell me you are going to do something, follow up with me about it. Let me know you did it, or whether there will be a delay. If we have not talked in a while, don’t assume everything is okay. In this type of work, no news is not necessarily good news.

5. Offer training opportunities beyond what’s required.
I love the blood borne pathogens training!! Who doesn’t? But there are so many more learning opportunities available (or which could be developed) that would be beneficial to me. I realize resources are limited. I know that time taken away from being with Theresa
means finding someone else to work with her. Still, ongoing learning experiences are important to support workers – to gain knowledge, to help me do my job better, to get rejuvenated, to meet other people.

6. I like my job and I want to keep it.
I like Theresa, and I like spending time with her. It is a good job, I do it well, and this is important to me. I don’t want to work in a job that I don’t like simply because I need income. I want to look forward to my job, at least most of the time, and be able to put positive energy into it. I’m telling you this because I think it’s important that you know how I feel about my work. I want you to know that I want to keep doing it, because if you know I’m invested in it, there is a greater chance that you’ll invest more in me, and that’s good for all of us.

7. Acknowledge my work and me.
Sometimes my work is extremely challenging. Sometimes, others don’t seem to believe that what I am doing is very important. There are days when it feels like no one cares that I’m here, doing my job – even Theresa. Please understand that at times I need encouragement or a pat on the back, or just someone to say, “What you do is important and valuable.” I may get messages from family, friends, society that tell me otherwise. So I need you to show me you care, that what I do makes a difference.

8. I don’t get paid a fair wage.
I’m not whining; I’m stating a fact. I knew the pay when I started, and I realize it may take a long time before this changes. But what can I do, and what can Theresa do, and what will you do, to work for change? Have you worked on this issue before? If so, tell me about it.

I know it’s not as simple as asking you for a raise. There is an institutional bias in this country, and community services, already under-funded, have seen cuts at state and local levels. Meanwhile, the cost of health insurance has skyrocketed. Who do I write to? Who do I call? Let’s advocate together.

9. I understand the need for an organizational hierarchy, but….
All employees have a place in the hierarchy; the buck has to stop somewhere. It looks to me like my job is at the bottom of the totem pole, or darn close to it.

If there must be a hierarchy, help me to not always feel that I’m at the bottom. My position here, and the others like it, is the closest on a daily basis to people with disabilities. We’re important. So, if on the organizational chart we need to be low, find ways to lift us up. Frankly, the chart doesn’t matter all that much to me. What matters is how I’m treated as an employee. Consider that it may also be best for Theresa if those of us from different places on the chart work collaboratively – if we acknowledge the chain of command but don’t dwell on it. If we mix it up here and there when possible. I’m not suggesting I begin telling the Executive Director what to do (though I’m not opposed to the idea!) but rather,
that those of you “above” us direct support workers respect us enough to understand what the hierarchy can sometimes feel like to us.

Here is one example: I’d been working with Theresa for a year when her case manager, my supervisor, quit. A new case manager was hired (with no input from me or Theresa, by the way) and began getting to know Theresa. It got a little awkward, me knowing Theresa pretty well by then and teaching my new supervisor some things, but my new supervisor telling me what to do. She needed to learn her job, which included supervising me, yet there were some things I knew more about. She had a hard time accepting that it would take her a while to learn everything she’d need to, and wanted to quickly put on the “supervisor hat.” I wanted to say, “Chill out! You’ll have plenty of opportunities to direct me!” But I didn’t.

10. Some flexibility is good for everybody.
My flexibility is important to you, and to Theresa. The need for it is inherent in this kind of work. So many things that go on in Theresa’s life rely on people to make them happen—people who, being humans, make mistakes and get stuck in traffic and get sick and oversleep.

So you ask me to be flexible, and this is reasonable. I think there are times when flexibility on your part is also needed. Not always, in every situation, no matter what. That would not be reasonable—just as it would not be reasonable for you to expect that I would be willing or able to change plans or schedules all the time. But it’s worth thinking about ways in which you, my agency, and you, my supervisor, can show flexibility toward me. After all, I’ve been here two years now, longer than the average direct support worker. And I’ve done a good job. I’m reliable, I have a good relationship with Theresa, and I bring a lot to my work.

Whether it concerns my job duties, or my schedule, or a time off request—whatever it may be, please consider the circumstances. Working together, with give and take, benefits all of us: you, Theresa, and me.